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Views and experiences of managing eczema: systematic review and thematic synthesis of qualitative studies

Running head: People's view of managing eczema

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What's already known about this topic?

- Eczema is a common skin condition that can have a substantial impact on quality of life.
- One of the most common causes of treatment failure in mild to moderate eczema is under use of topical treatments.

- Increasingly, qualitative approaches have been adopted to understand people's views and experiences of eczema and eczema treatment, which can help to address common barriers and support effective self-management.

What does this study add?

- We found a large volume of qualitative studies giving valuable insights into people's perceptions of eczema. Synthesising these highlights many recurring themes and adds further insights, for instance different perceptions between adults with eczema and parents of children with eczema on its long-term nature.
- Eczema can be difficult to manage due to treatment hesitancy and burden and misperceptions about the long-term nature of eczema.
- Hesitancy or concern about eczema treatments is made worse by insufficient and inconsistent information and advice.

What are the clinical implications of the work?

- Health professionals need to address common treatment beliefs and concerns and seek positive ways to promote a 'control not cure' message to support effective ongoing self-management.
- Acknowledging the significant psychosocial impacts of eczema and burdensome nature of treatment and providing clear consistent information and advice or signposting towards credible information may address people's concerns that distress caused by the condition is not taken seriously.

SUMMARY

Background: The number of qualitative studies on eczema has increased rapidly in recent years. Systematically reviewing these can provide greater understandings of people's perceptions of eczema and eczema treatments.

Objectives: We sought to systematically review and thematically synthesise qualitative studies exploring views and experiences of people with eczema and parents/carers of children with eczema.

Methods: We searched MEDLINE, PsycINFO, CINAHL and EMBASE from the earliest date available to February 2019. We selected papers focusing on views and experiences of eczema, eczema treatments, and barriers/facilitators to eczema self-management. We excluded papers focusing on health service provision models or health professionals' views.

Results: We synthesised 39 papers (reporting 32 studies) from 13 countries. We developed four analytical themes: 1) Eczema not viewed as long-term condition, 2) Significant psychosocial impact not acknowledged by others, 3) Hesitancy (patient/carer uncertainty) about eczema treatments and 4) Insufficient information and advice. Our findings suggest people with eczema and their carers experience frustration at having to manage a condition that is often seen by others as mundane but has significant psychosocial impact and is difficult to manage due to concerns about, and burden of, treatment. This frustration can be exacerbated by experiences of conflicting and/or insufficient information and advice from health professionals, family and others.

Conclusions: Effective self-management of eczema could be supported by addressing beliefs and concerns about treatments; seeking positive ways to promote a 'control not cure' message; acknowledging psychosocial impacts of eczema and treatment burden; and providing clear consistent advice or signposting towards reliable information.

INTRODUCTION

Eczema is common and can have substantial impact on quality of life due to itch and sleep disturbance.¹ Eczema management involves applying topical treatments and avoiding triggers (e.g. soap).² NICE guidance² suggests the main cause of treatment failure is due to underuse of topical treatments.³ Treatment usage is related to people's understanding of their condition and its treatment, as well as perceived need for treatments and concerns about any negative effects.⁴ Surveys have found that people with eczema worry about using topical corticosteroids,^{5 6} yet relatively little is known about the reasons behind this.

Qualitative research seeks to gain a comprehensive understanding of people's lived experiences of a condition. Greater understanding of their perspectives on treatments may help to promote a 'shared understanding' and identify narratives that could mitigate against increasingly polarised views about eczema treatments that have emerged between patients/carers and health professionals.^{7 8}

Synthesising the results from existing qualitative research studies helps to generate new valuable insights into people's beliefs and concerns, and their support and information needs.^{9 10} We aimed to synthesise existing qualitative studies exploring the views and experiences of eczema and eczema management amongst people with eczema and parents/carers of children with eczema.

METHODS

Thematic synthesis was used to synthesise the review findings.¹¹ We followed the ENTREQ statement¹² to facilitate reporting.

Selection criteria and search strategy

We included papers that primarily focused on the views and experiences of eczema and eczema treatments, and barriers/facilitators to eczema self-management. To be eligible for inclusion, studies must have used qualitative data collection and analysis methods. Mixed methods studies were included if they had a substantive qualitative component. Papers that focused solely on health service provision models or the views/experiences of health professionals were excluded (Table 1).

Five electronic databases were searched using a comprehensive search strategy (supplementary material A): Medline (1946 to February week 2 2019), PsycINFO (1887 to February week 3 2019), Embase (1980 to 2019 Feb 27) and CINAHL (1982 to February week 4 2019). The last search was conducted on 27th February 2019. There were no language or date restrictions. We reviewed references of each included paper, conducted forward citation tracking and contacted experts in the field to identify other eligible papers. Multiple papers from a single study were included if each presented unique data. Two eligible studies (published in German and Korean) were translated into English by a professional translator. Three authors independently screened all titles and abstracts against the inclusion criteria (ET, NF plus either SW or IM).

Comprehensiveness of reporting

Two authors (ET, DG) and two student research assistants (NW, LS) independently extracted data and appraised the reporting quality of identified studies. We used the COREQ (Consolidated Criteria for Reporting Qualitative Research)¹³ checklist to systematically examine comprehensiveness of reporting to judge the trustworthiness and transferability of the studies. Any discrepancies were resolved by consensus. No studies were excluded on grounds of quality.

Thematic synthesis

We imported the findings from each paper (including participants' data and author interpretation of findings) into NVivo version 12. Thematic synthesis¹¹ comprises three distinct stages: line by line coding, developing descriptive themes from initial codes and generating analytic themes that 'go beyond' the descriptive themes. A detailed coding manual ensured transparent and systematic data coding. Coding, descriptive themes and subthemes were discussed with, and iteratively developed by co-authors (MS, AR, MR, KT, LY, KS, DG, KG) to offer diverse inferences and interpretation of the data, and facilitate the generation of analytic themes.

RESULTS

Our searches yielded 2,241 records (1,569 after duplicates removed). Eligibility screening identified 39 papers reporting 32 studies for inclusion (Figure 1).

Study characteristics and comprehensiveness of reporting

Included studies explored the views and experiences of 1,007 participants including 405 parents/carers of children with eczema, 252 people with eczema and 350 online forum users. Study characteristics are presented in supplementary material B. The comprehensiveness of reporting was mixed. Participant selection, setting, data analysis and findings were well-reported, whilst interviewer characteristics and relationship with participants were poorly reported (supplementary material C).

Synthesis of findings

Our synthesis identified four over-arching analytical themes: 1) Eczema not viewed as a long-term condition, 2) Significant psychosocial impact of eczema not acknowledged by others, 3) Hesitancy (patient/carer uncertainty) about eczema treatments and 4) Insufficient information and advice about eczema (Figure 2). Table 2 presents quotes from study participants to illustrate each theme and subtheme. Further theme tables are provided in supplementary materials D

Eczema not viewed as a long-term condition

A common perception highlighted in the synthesis was that people with eczema often do not view eczema as a chronic condition requiring long-term treatment. Research with parents and children identified hopes of outgrowing eczema and/or experiences of being told they would outgrow eczema. Participants hoped to discover an underlying cause of eczema to 'cure' eczema, which further contributed to a perception of eczema as short-term. This had implications for perceived necessity of long-term treatment and was linked with frustration at the perceived 'simplicity' of eczema management in targeting symptom control rather than underlying causes.

Desire to seek an underlying cause and potential 'cure' for eczema

A diverse range of beliefs about underlying causes of eczema was reported including exogenous factors (dietary allergens, chemicals, medication and water type) and endogenous factors (genetic disposition, stress/psychological factors). A common belief amongst families was that dietary avoidance might represent a potential 'cure'; many described having tried this and described frustration with healthcare professionals' perceived lack of interest in exploring dietary causes. ^{19 23 26-28 31 33 36-37 46 55-57}

Frustration at perceived simplicity of eczema treatment

Frustrations were identified with treatments viewed as only 'controlling' eczema rather than providing a 'cure'. ^{32 36 38 42 45} One study ⁴² outlined a paradox of complexity and simplicity, whereby living with eczema is experienced as complex in terms of impact and treatment burden, but people perceive that they are offered only simple 'Band-Aid' solutions that do not treat the underlying cause. Such beliefs represent potential challenges to adherence to long-term eczema treatments.

Significant psychosocial impact of eczema not acknowledged by others

People across studies were frustrated at the lack of recognition and acknowledgment by both health professionals and wider society of the significant physical and emotional impacts of eczema on people with eczema and their families.

Perceived impact on physical and emotional well-being

Physical impacts of eczema commonly described across studies were persistent itch, pain and discomfort due to dry skin, chronic sleep disruption for people with eczema, and parental exhaustion from attending to their child's needs at night.

Significant emotional impacts of eczema were experiencing distress, low mood and self-esteem due to feeling stigmatised and self-conscious about their appearance and feeling that they do not fit a societal ideal of 'perfect' skin, and the resultant effect this can have on relationships. Studies also highlighted the negative effect of dealing with others' perceptions and distress experienced in response to intrusive comments or reactions by strangers to visible eczema, such as fear of contagion. A sense of blame, guilt and worry were common, especially parental feelings of inadequacy in their ability to prevent the eczema, envy of other parents with perceived 'normal' children and fears and concerns about the impact on their child's self-esteem and social interactions. ^{21-23 26 28 31-33 39 41 43 46-47 49-50 52-56}

Perceived impact on everyday routines/family life

Participants commonly reported changing behaviours and modifying everyday routines in response to eczema symptoms, in a desire to avoid potential irritants and adhere to treatment regimes.^{19-25 28 39 42 56}

Studies highlighted participants' experiences of restricting social activities, work activities or career choices to prevent flare-ups. In contrast, a desire to live an 'ordinary' life and not let eczema impact on routines or behaviours was evident in some studies.

As well as restricting or giving up certain activities, a common impact amongst parents was dealing with extra burden on daily life of caring for a child with eczema.^{19-25 28 39} Many parents described how carrying out extra tasks to manage their child's eczema e.g. applying topical treatments, extra washing and cleaning, buying particular clothing.

Practical barriers to topical treatment use

Treatment burden and its impact on people with eczema and family life was apparent along with a sense that this burden was not acknowledged by others.^{19-20 23 25 33 42 46 54 55} A dominant experience was around perceived difficulties in applying topical treatments, particularly due to its time-intensive nature and amongst parents of younger children, the challenge of child resistance due to discomfort/pain/stinging or 'just being a toddler'. Some studies found that the burden of treatment related more broadly to additional activities needed to manage eczema; 'just something else you have to remember to do', e.g. always being alert to avoiding possible triggers. These were viewed as energy or time-consuming, resulting in attention for other children and/or family members. Parents also found maintaining treatment routines outside the home difficult as they felt that their childcare or school was ill-equipped to manage treatment routines and avoid triggers.

Perceived trivialisation/dismissal of eczema by others

A dominant belief was that eczema is misunderstood or dismissed as trivial by health professionals, friends, family, and wider society as 'just a bit of dry skin'.^{21-23 26-28 30-32 36 48-54 56} Some studies highlighted how parents felt that family and friends normalised sleep loss as being a normal part of parenting, failing to recognise chronic sleep loss as related to eczema. Others highlighted the perception that eczema is viewed in society as a mundane, insignificant condition, common in childhood (i.e. most people know a child who has it mildly) and as such it is something that people should 'cope' with. This was linked to accounts of family, friends or strangers giving unsolicited advice about eczema.

Hesitancy (patient/carer uncertainty) about eczema treatment

Many studies reported common concerns, doubts and perceived difficulties around eczema treatment, reflecting an implicit caution and uncertainty about topical treatments, particularly topical corticosteroids, and a general hesitancy towards regular or long-term treatment. This hesitancy seemed to be exacerbated by having received negative or conflicting advice about topical treatments from health professionals and significant others.

Concerns about the perceived risk of topical corticosteroids

A dominant concern was that using topical corticosteroids can lead to skin damage, particularly skin thinning and possibly other long-term negative effects e.g. weakened bones, weight gain and delayed growth. These seemed to be influenced by a shared belief or social discourse that topical corticosteroids should be treated with caution and apprehension.^{25 32 36-38 43 45} Some studies highlighted how participants felt their concerns had been reinforced by negative attitudes of health professionals and significant others delivering messages such as the 'risks of topical corticosteroid use outweigh the benefits'. Despite such concerns, some studies found that whilst people were concerned about potential risks, they found topical corticosteroids helpful/effective in managing their eczema and saw them as a 'necessary evil'.

Uncertainty about appropriate use of topical corticosteroids

Participants reported a lack of confidence and low self-efficacy in applying topical corticosteroids. This was related to uncertainty and confusion about the appropriate use of topical corticosteroids in terms of dosage (e.g. strength/potency of different preparations), where to apply, when to use, duration of use and what constitutes a 'thin layer'.^{32 36-38 45}

Concerns about the constituents of emollients

Some studies highlighted people's concerns about the constituents of emollients, the unpleasant feel (thick, greasy, messy) and odour of emollients and their uncertainty/confusion about the range and choice of different emollients.^{19-20 23 25 31-33 35 37-38 42 44 46-47 54-55} Some participants felt that emollients are unnatural products containing chemicals and expressed a desire for more 'natural' creams that they deemed to be safer, or other treatments for eczema such as special clothing. Other studies identified people's mixed feeling towards the range of different emollients creams and resultant process of 'trial and error' in finding the 'right' cream.

Doubts about effectiveness of topical treatments

Many participants expressed doubts about topical treatments as being 'just some creams' and perceived them as ineffective or even that they make the eczema worse. Some studies highlighted a belief around becoming 'resistant' to both emollients and topical corticosteroids if used regularly or long-term (i.e. skin becomes 'used to' treatment and treatments lose effectiveness). Topical corticosteroids were frequently viewed as effective only in the short-term. A common frustration was that once you stop using them, the eczema just flares up again, causing some to worry about 'dependency'. In contrast, some studies highlighted perceived effectiveness of topical corticosteroids in terms of symptom relief and belief that topical corticosteroids are safe and effective if used correctly and that uncontrolled eczema is a greater threat to skin than treatment. ^{31-32 36-40 42 43 46 57}

Strategies to overcome perceived difficulties and concerns

As well as highlighting perceived difficulties, some studies proposed strategies to address difficulties and help facilitate topical treatment use. ^{20 23 25 30-31 33 35} One study ³³ described a range of responses that families adopted to overcome their child's resistance to topical treatments including involvement of the child in treatment; distraction or games; using 'bribes' and, in a few cases, force. Other studies highlighted general beliefs about what may make eczema treatment times easier such as establishing a routine, i.e. sticking to daily treatment times to establish habits and finding the right treatment by trial and error, i.e. discovering what works for person with eczema in terms of effective, convenient topical treatments that fit with daily life.

Some studies found that participants tried to make personal adjustments/'do their own thing' (e.g. reducing dose) to help mitigate their concerns and uncertainty about topical treatments. ^{42-45 47 55-57}

Modifications to treatment regimens included using creams that are less strong (or perceived to be less strong), delaying application of topical corticosteroids for as long as possible and reducing frequency of emollient application. Although modifying treatment regimes may lead to a sense of increased confidence and self-efficacy, it may contribute to the under-utilisation of topical treatments and poor eczema control.

Receiving conflicting and negative advice about topical treatments

Our synthesis revealed common experiences of receiving conflicting advice (contradictory opinions) and/or negative opinions from health professionals regarding topical treatments, especially around the safe use of topical corticosteroids.^{20 25-26 31-32 34 37-38 44-45} Conflicting advice was received from different health professional specialties (e.g. primary care, paediatricians, dermatologists, pharmacists), from different individuals within the same specialty (e.g. different GPs), or between health professionals and other sources (e.g. product information leaflets and medical websites). This seemed to exacerbate concerns and uncertainty about applying topical corticosteroids, which is likely to influence treatment use. Some studies suggested that conflicting advice can lead people to seek information and advice elsewhere such as online, despite their doubts about the credibility of online information, which may add confusion.

Insufficient information and advice about eczema

Information and support provided by health professionals was commonly seen as suboptimal in terms of quantity, detail and timing. Our synthesis highlighted participants' desire to have more up-to-date, personalised information about treatment, identifying flare-ups, and other aspects of living well with eczema (e.g. strategies to reduce itch) as well as practical advice around applying topical treatments, including demonstrations from health professionals.^{21 23 26 29-32 34-36 38-40 44 47-48 55}

Participants typically expressed a desire for patient-centred management of eczema or shared decision-making. However, one study⁴⁷ noted that in the absence of sufficient eczema information provision and support can be experienced negatively, with participants experiencing 'involuntary autonomy' i.e. feeling 'left to your own devices' and having to self-manage by default.

DISCUSSION

Our evidence synthesis highlights that people living with eczema, particularly young people and parents of children with eczema, often do not see eczema as a long-term condition. People are cautious about topical treatments for eczema, especially topical corticosteroids and this appears to be exacerbated by experiences of conflicting and inconsistent advice from health professionals and others. People with

eczema and their carers feel frustrated when others view eczema as mundane, insignificant or 'easy', while it has significant psychosocial impact.

Strengths and weaknesses of this study

This systematic review and synthesis of qualitative studies provides a comprehensive overview of a sizeable qualitative literature on eczema and valuable insights into views and experiences of managing eczema from the perspective of children and adults with eczema, and parents/carers of children with eczema. We used rigorous systematic review methods and identified many well-reported studies from different countries. Key themes were reported across many of the papers, suggesting our findings are robust. Valuable input from patient contributors and multidisciplinary team enabled comprehensive interpretation of findings.

We only included studies from peer-reviewed journals and did not search the grey literature. We did not apply any language restrictions to our search and included some non-English language papers, but we may have missed relevant papers not recorded on English language databases. As with other reviews, we are limited to data in the included primary studies, which were predominantly conducted in European countries. The synthesis process is inherently interpretive, and this synthesis presents one possible interpretation of the data. Our study was undertaken as part of a larger project to develop online resources to support eczema self-care, which may have influenced our interpretations. Another research team would likely generate a different interpretation.

Comparison with other studies

Our findings are supported by a previous synthesis of qualitative studies of treatment adherence, which suggests that people dislike taking regular medication or treatment on a long-term basis as it reminds them of the chronicity of their illness, which many do not accept.¹⁴ It may be that the perception of needing to limit use of other types of medication, such as antibiotics (due to antibiotic resistance), may fuel people's general reluctance to taking medication and so clear, consistent advice about eczema treatments is needed.

It is interesting to note that it was often parents and young people who focused on a 'cure' for eczema. It is likely that adults with eczema had been living with the condition for longer and had more experience of

its long-term and fluctuating nature. Commonly reported messages around 'you or your child will grow out of it' can feel like dismissal, especially when mismatched with actual experiences. Traditional clinical teaching promotes eczema as primarily a childhood condition that generally remits by age 10 to 12 years.¹⁵ However, recent research suggests this may not be true for many.¹⁶ Managing expectations accordingly might help reduce disappointment for those who don't grow out of it.¹⁷

Conclusions and implications for research and practice

Much qualitative research on eczema has focused on the views and experiences of adults and parents/carers. Although more recent research has shed light on the impact of eczema on children¹⁸, further research is needed from children's and young people's perspectives. There is a need for health professionals to address beliefs and concerns about eczema treatments, address the significant psychosocial impacts of eczema and burdensome nature of treatments, including practical, clear, consistent advice about treatments and strategies to overcome perceived difficulties.

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Review registration: The protocol for this systematic review was registered on PROSPERO (CRD42018110496) on 21st September 2018.

Contributors

ET developed and refined the protocol, undertook the systematic review, data extraction, quality assessment, carried out the thematic synthesis, and drafted the manuscript. MS participated in the design of the study, provided guidance in the thematic synthesis, participated in the interpretation of findings and contributed to writing the manuscript. IM, SW and NF participated in the eligibility screening process. DG, SW and NF participated in data extraction and quality assessment. IM, KS, KG, DG, AR, MJR, LY, KT participated in the interpretation of the findings and critical review of the manuscript. All authors read and approved the final manuscript. ET and MS are the guarantors.

Ethical approval

None required

Public and Patient Involvement statement

Our patient collaborator (AR) was involved in all aspects of the study from attending early development meetings and contributing to study design through to her valuable contributions to interpreting the findings.

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TABLES

Table 1: Inclusion and exclusion criteria

	INCLUSION CRITERIA	EXCLUSION CRITERIA
Population of interest	<ul style="list-style-type: none"> • Children with eczema • Young people with eczema • Parents/carers of children with eczema • Adults with eczema 	<ul style="list-style-type: none"> • Health professionals' views only
Exposure of interest	<p>Eczema and eczema self-care</p> <ul style="list-style-type: none"> • Eczema • Emollient use • Topical corticosteroid use • Topical calcineurin inhibitor use • Avoidance of triggers • Emotional/stress management • Reducing scratching • Psychosocial impact of eczema only • Accessing health services, treatment, dealing with healthcare professionals 	<ul style="list-style-type: none"> • Models of health service provision
Outcome of interest	<ul style="list-style-type: none"> • Patients and parent/carers' beliefs, views, concerns, understandings and experiences 	
Study design	<ul style="list-style-type: none"> • Qualitative (<i>including ethnography, grounded theory, phenomenology, focus groups, interviews and participant observation</i>) • Mixed methods 	<ul style="list-style-type: none"> • Quantitative • Reviews • Not primary research

Table 2: Illustrative quotes by theme

THEME AND SUBTHEME	REPRESENTATIVE QUOTES
Eczema not viewed as a long-term condition	
<i>Desire to seek an underlying cause and potential 'cure' for eczema</i>	<p><i>"The condition of my AE child is getting worse. I try my best to relieve his suffering. Some mothers have told me that the chlorine in the water supply and the water pipes affects AE. So, I replaced the water pipes and use a filter, and his condition is getting better now."</i> ²³</p> <p><i>"I just, I wanted to know really why was she getting it, was it diet orientated because it seemed to crop up at the same time as I was weaning her, and I thought she might have an allergy to milk or, you know that milk I was using, or perhaps some of the, the fabric conditioners or, you know, or the baby bath I was using, something like that."</i> ²⁶</p>
<i>Frustration at perceived simplicity of eczema treatment</i>	<p><i>"The frustrating thing with TCs [topical corticosteroids] is that they don't really treat the disease. They provide relief but they don't heal"</i> ⁴⁵</p> <p><i>"I don't like that it only treats the symptoms and not the cause of the problem"</i> ³⁸</p>
Significant psychosocial impact of eczema not acknowledged by others	
<i>Perceived impact on physical and emotional well-being</i>	<p><i>"She hardly got any sleep, she scratched herself, and she was at a point where she couldn't keep up at school. She was totally exhausted, which affected her mood."</i> ⁴⁷</p>

THEME AND SUBTHEME	REPRESENTATIVE QUOTES
	<p><i>"I sometimes feel so ugly when everything is stuck together, I am like a monster. I don't want anybody to see me and I don't want to go out."</i> ⁵⁶</p>
<p><i>Perceived impact on everyday routines/family life</i></p>	<p><i>"There are many things which you have to give up. That is, I liked knitting and I liked to cook and make pickles and jam. I was very, you know, active with my hands. I don't bother to do these things anymore because it's far too troublesome."</i> ⁴²</p> <p><i>"The very fact the she does not sleep means that we very rarely go out. The few occasions we do go out K's grandma will baby-sit, but this extremely tiring for her and therefore we do not ask often"</i> ²⁴</p>
<p><i>Practical barriers to topical treatment use</i></p> <ul style="list-style-type: none"> – <i>Child resistance</i> – <i>Time intensive nature of eczema treatment</i> – <i>Difficulties of using topical treatments outside of home environment</i> 	<p><i>"It is very difficult to apply the cream to my son as he always fights with me and runs away from me when I am trying very hard to keep his skin moist. Sometimes I have to wait and apply the cream at 2 am when he is asleep."</i> ²³</p> <p><i>"If I was having a bad day and it would take 2 hours in the morning just to cream her up and to get the routine done, it was just ... I was so exhausted and you've still got to do everything else and life and fit it all in. It could be quite hard..."</i> ³³</p> <p><i>"I think [the daycare providers are] limited on what they can and can't do for a child with eczema during the day.... That's one of the most problems I have...to keep shine to her, you have to apply lubrication all day."</i> ²⁵</p>

THEME AND SUBTHEME	REPRESENTATIVE QUOTES
	<i>"In spite of relevant precautions at work, one participant had an eruption, interpreted as work-related, from touching a door handle where a colleague could have left residue of the allergen. 'One can't control other people's actions [...]no matter how many labels you read [...]"</i> ⁴²
<i>Perceived trivialisation/dismissal of eczema by others</i>	<p><i>"There's nobody else and they don't understand how it is (...) They don't even believe before they see it, my coach thought I was exaggerating."</i> ⁵⁶</p> <p><i>[Health professionals say] "No, no it's just dry skin", "Oh, it's just eczema" I don't think they realize how much children can suffer from it"</i> ²⁶</p> <p><i>"And then it got to the point where my mother actually took her in because I was getting nowhere with the doctor, he kept on fobbing me off with rubbish, you know, "She'll grow out of it", yeah but that doesn't help now."</i> ³²</p>
<i>Hesitancy about eczema treatment</i>	
<i>Concerns about the perceived risk of topical corticosteroids</i>	<p><i>"It makes your skin wither...Will they tell you later on that you shouldn't use D... fear that in a few years it could give you something...that we don't know about for now... medicine evolves."</i> ⁴⁵</p> <p><i>"My baby started getting eczema over the last month or so. My GP suggested [leave-on emollient] and I am using loads of it, but I</i></p>

THEME AND SUBTHEME	REPRESENTATIVE QUOTES
	<i>don't think it's doing anything. I asked the GP if there's anything else I can try because I thought it might be worth trying a mild steroid cream, but my doctor advised against it because the risks (skin thinning) outweigh the benefits."</i> ³⁷
<i>Uncertainty about appropriate use of topical corticosteroids</i>	<i>"I did ask once what exactly is a thin layer?"</i> ³⁸ <i>"I guess the question is when to use steroids. The doctors always said to only use them for a few days at a time. When a patch flares up the steroids generally help within a few days, but then we find that another small patch has flared up somewhere else on his body so we end up using the cream for ages but in different places if that makes sense."</i> ³⁷
<i>Concerns about the constituents of emollients</i>	<i>"My son uses emulsifying ointment as a protective layer for his skin. My approach would be different if it were made of a different substance. Some are made from natural materials but some are chemical products. I can distinguish between the two just by smelling!"</i> ²³ <i>"— I'm not into kind of putting loads of chemicals on them if I can possibly avoid it, which is why I think in the end my solution was if it's really bad I'll use the cream but otherwise I'll just stay away from anything I put on his skin and look at diet first and then kind of consider that."</i> ³² <i>"Sometimes it's annoying, especially in the morning, because greasy spots appear in my trouser due to the creams."</i> ⁵⁵ <i>"...the other creams, we had a couple, I think it was E [ointment], I'm not sure, but it was really thick, like Vaseline [ointment], they were quite difficult—they're really thick, greasy, really hard to apply, cos that ruined loads of clothes, so you had to wash things. That</i>

THEME AND SUBTHEME	REPRESENTATIVE QUOTES
	<i>was quite hard work at the beginning, I'd say."</i> ³⁵
<i>Doubts about effectiveness of topical treatments</i>	<p><i>"Sometimes we are advised to use steroids for x long... then as soon as stops everything flares up again. Not a long-term solution really."</i> ⁴⁶</p> <p><i>"At this moment, I feel like the effect is becoming weaker. Because as soon as I start to reduce the amount, it comes straight back"</i> ³⁸</p>
<i>Strategies to overcome perceived difficulties and concerns</i> <ul style="list-style-type: none"> – <i>Distraction, disguising treatment</i> – <i>Establishing a daily routine</i> – <i>Personal adjustment of treatment regimes</i> 	<p><i>"I usually rub it on and let it dry for 2 seconds. [...] rub it on sort of like in a car wash. Apply polish and dry."</i> ⁴⁴</p> <p><i>"Well, not everyone feels like this, right. I think it's a habit, but with the mobile phone you can set more than one alarm. I have begun to set it thrice a day. At least in the evening, because then the phone hoots even if you have gone to bed. Well – put on the cream and the gloves."</i> ⁴²</p> <p><i>"I don't apply it until my comfort threshold has been exceeded and I'm all red and it itches all over"</i> ⁴⁵</p>

THEME AND SUBTHEME	REPRESENTATIVE QUOTES
<i>Receiving conflicting and negative advice about topical treatments</i>	<p><i>"I saw this one doctor who said that we should use the [mild topical corticosteroid] on red inflamed skin and that we should use [potent topical corticosteroid] anywhere where the skin is actually broken. But then I saw another GP who told me not to use [potent topical corticosteroid] unless it is really bad because it is so strong and it would damage the skin. Could anyone please give me a clear answer about when I should use an emollient, or a mild steroid or a stronger steroid?"</i> ³⁷</p> <p><i>"I was disappointed when the paediatrician said, 'It's nothing serious, but unfortunately, we'll have to use cortisone. . ' when he said 'unfortunately'"</i> ⁴⁵</p>
<i>Insufficient information and advice about eczema</i>	
<i>Perceived suboptimal eczema information provision</i>	<p><i>"I just wish that the GP at the beginning had recognized it more quickly and explained more about the importance of emulsifying and, erm, proper use of the hydrocortisone really, that's the one thing that stands out."</i> ²⁶</p> <p><i>"It would be good if they showed you how to apply the cream, when collecting it for the first time."</i> ⁵⁵</p> <p><i>"I kind of feel that... it's not come back in, say, 2months' time and we'll review whether it's making a difference or not ... I have felt some of the time that I'm making it up as I go along...."</i> ³²</p>

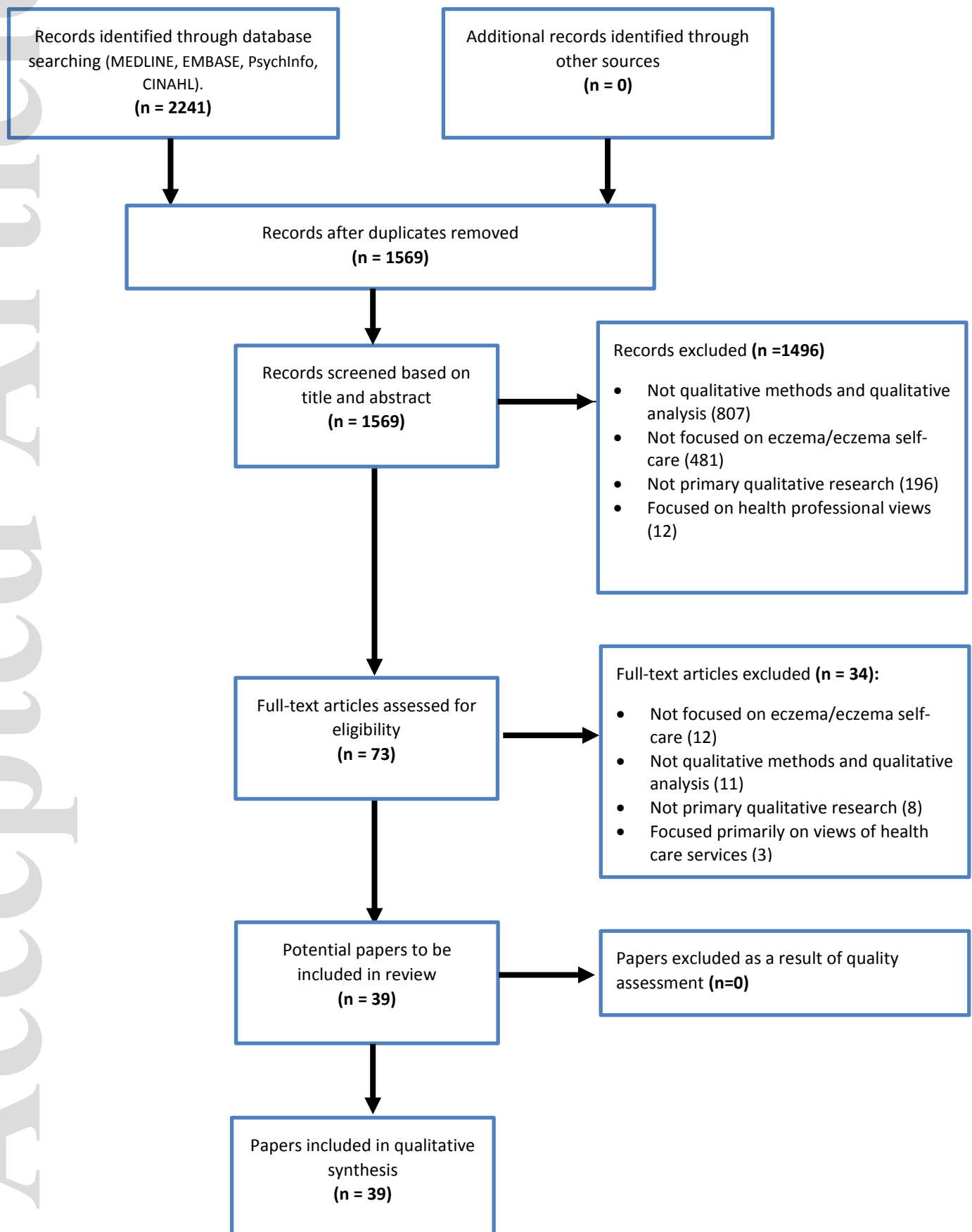
Figure 1: PRISMA Flowchart for systematic review and qualitative synthesis

Figure 2: Components of key themes

